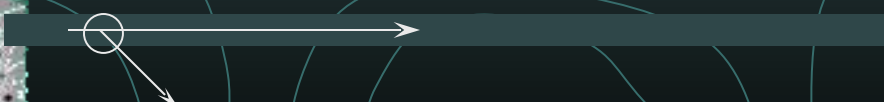




Use of Scientific Review Board to Promote Use and Exchange of Data on the Utah EPHT Network



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Purpose

In recognition of the need for an entity which would protect the confidentiality of both the data contributor and the data subject as required by law, and to ensure the scientific validity of the use of the data, the Utah Department of Health administers the Utah EPHTP Scientific Review Board to manage the collection, use and disposition of that data by research and public health projects.

Concerns Expressed by Data Partners

- Validity of conclusions drawn from linked data.
- Erroneous correlations of health effects to environmental exposure.
- Indiscriminate distribution of maps of environmental data linked to health data without appropriate scientific interpretation.
- Ensuring protection of confidential data.
- Indiscriminate release of data.
- No peer review of published results using data provided by data sharing partners.
- Results contradict agency objectives.
- Agency action will be required based on results, for which no funds are available.
- Participation in network will incur additional costs.

Description

- The SRB comprises a panel of data stewards appointed by organizations that contribute data to the Utah EPHTN. Each data owner on the EPHTP will appoint one representative from their agency to represent their data in the EPHTP Scientific Review Board.
- Organizations or individuals desiring access to Utah EPHT data must apply to, and receive approval from, the SRB before access to the data is granted.
- The SRB protects the confidentiality of the data and ensures that studies utilizing the data are scientifically sound.

Scientific Review Board Members

- PI Utah EPHTP
- Utah EPHTP Manager:
Executive Secretary
- Director, UDEQ Division
Water Quality
- Director, UDEQ Division Air
Quality
- Director, UDOH State Public
Health Laboratory
- Director, UDEQ Division of
Emergency Response and
Remediation
- Director, Utah Cancer
Registry
- Director, Utah Birth Defect
Network
- Director, Office of Vital
Records
- Director, Office of Health
Care Statistics
- Medicaid Representative

Responsibilities of SRB

- Development of policies and procedures for:
 - maintaining privacy of subjects and confidentiality of human health data.
 - data security and management that meet the standards of the individual data owners.
- Review applications for data access and study proposals to ensure inclusion of measures to protect and appropriately use data from the UEPHTN.
- Review reports and publications using data from the UEPHTN.
- Authorize release of reports and papers.

SRB Approval Process

- Projects including human subjects or records of human subjects must submit and gain approval by the Institutional Review Board of sponsoring institution.
- Access to individually identifying information must be specifically requested and justified. Request for access must include the time period for which access is requested.
- Strong justification must be made for access to individual identifiers. Such requests should indicate why the project could not reasonably be conducted without such access. The time period of time for access must be tied to project methodology.
- Changes in project procedures that may affect the protection of the privacy and confidentiality of data subjects require a written request for amendment and EPHT approval.
- Projects or requests that intend to link data to other EPHT protected data or intend to use linked data are subject to review.

SRB Approval Process

- Proposal submitted to SRB for review.
- Utah EPHT application form
 - ✓ Person responsible for the project
 - ✓ Start and end dates of the project
 - ✓ Performance site
 - ✓ Data to be accessed and for how long
 - ✓ Procedures for data access
 - ✓ Procedures for assurance of data security
 - ✓ Procedures for contacting individuals (if applicable)
 - ✓ List of all personnel who will have access to the data, specifying those who will have access to individually identifying data (if applicable)
 - ✓ Plan for disposition of data at the end of the project

How Will The SRB Promote Data Use And Exchange?

- ✓ Provides EPHTP with a committee of subject matter experts to assist in guiding the content priorities including data elements, analytical tools, linkage methodology and professional expertise for the network.
- ✓ Provides peer credibility to the EPHTP efforts to recruit data sharing partners and promote the EPHTP among data users.
- ✓ Instills confidence in data partners that studies utilizing their data are scientifically sound.
- ✓ Confidence in data sharing partners in the ability of the EPHT Program to ensure the security of contributed data.
- ✓ Empowers data sharing partners with control of access, use and distribution of data.
- ✓ Increase the quantity and quality of data available through the Utah EPHT Program.
- ✓ Ensures scientific validity of use of the data.

SRB Plan

The SRB plan addresses:

- Organization, governance and membership of the SRB.
- Appropriate standards, policies, regulations, rules and statutes for protection of private, personal and confidential data contained within the UEPHTN.
- Scientific review methods and guidelines for ensuring that data use proposals and projects are meeting those standards.
- Methods to ensure and improve data quality.
- Procedures to receive, review and approve requests for access to and use of UEPHTN data.

Challenges

- Development of Data Sharing Agreements requiring participation on the SRB.
- Participation on the SRB by data contributors.
- Development of a streamlined review and approval process that facilitates the release of data and publications.

Conclusion

Forming the Scientific Review Board gives the data contributors control over their data, and ensures scientific integrity in the use, interpretation and publications using EPHT data. This in turn increases participation by data stewards in the Utah Environmental Public Health Tracking Program.